

February 25th, 2015

To: CT Legislative Committee Members

Re: CT House Bill #6100 "An Act Designating Spinal Muscular Atrophy With Respiratory Distress Awareness Day"

From: Karen Drao, BS, RRT
Bioscrip Professional Homecare

Dear Members of the Committee,

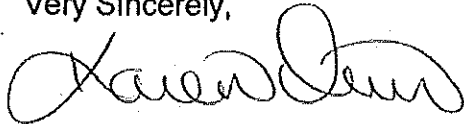
I am writing this letter in strong support of the passage of proposed House Bill 6100, An Act Designating Spinal Muscular Atrophy With Respiratory Distress Awareness Day. I have been providing respiratory care and support for 9 year old, Hunter Pageau, since he was 2 years of age and then discharged from the hospital to home on 24 hour ventilator support, concluding a year long continuous hospital stay. Despite the very impending and aggressive documented disease characteristics, Hunter has essentially defied the medical odds based on his disease profile, with the steadfast dedication of his family and specialty medical team. Hunter is truly a pioneer for this orphan disease.

I am discouraged to report there continues to be very limited documented medical information, available to either the medical community or the community, at large, regarding SMARD. Additionally, with SMARD still being vastly unknown, and for reasons of lack of awareness of this identified rare disease, it is often confused with a different disease, SMA, due to the name similarity. Please note that SMARD is a separate, extremely rare disease, with separate genetic markers, thus requiring it's own individualized care protocols, research for a cure, and educational opportunities, in order to meet the demands of this particular disease.

With SMARD presenting with physical disabilities only, Hunter is a bright, engaging, positive, determined child whom is incredibly willing to be the face of SMARD, in an effort to valiantly support those with SMARD, their families and their communities in also successfully battling this disease. He wants the world to know that despite being diagnosed with a disease of this magnitude, it does not have to equate with a terminal life or existence. He is entirely committed to living a life of equality, opportunity and joy, likewise to his non-disabled peers. While immense sacrifices and hardships have been faced by both Hunter and his family, they continue to bravely battle this significantly aggressive disease, with a positive and hopeful attitude. It is imperative to increase awareness of SMARD, in order to create a solid platform to provide the very much needed opportunities for education and research for a cure. The passage of House Bill 6100 is vital in the noteworthy pursuit of this respected and needed endeavor.

I strongly encourage you to support and honor Hunter's pursuit of raising the very much needed awareness of SMARD, so that he may not only continue to be a shining example of brave perseverance, strength and hope for others with SMARD, but for all of our Connecticut neighbors. In caring for Hunter, I have watched in awe of his continuous ability to overcome what was considered to be insurmountable obstacles by most, and deeply inspire many others. While he and his family have fought passionately and endlessly to raise awareness for SMARD, and share Hunter's message of Hope, Love and to Never Give Up, their efforts alone are not sufficient in achieving their goal of increasing SMARD awareness on a greater level. Thank you for your kind consideration of support for this bill, so as to assist with accomplishing what this amazing family has begun a decade ago, of statewide outreach for increasing SMARD awareness. No family in our state should ever have to go through what they have endured, due to lack of awareness of this disease.

Very Sincerely,

A handwritten signature in cursive script, appearing to read "Karen Drao".

Karen A. Drao, BS, RRT